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Radiation Therapy and Psychological Distress in Gynecologic Oncology Patients: Outcomes and Recommendations for Enhancing Adjustment

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Summary

Radiotherapy is used commonly in the treatment of gynecologic malignancies. Many patients experience emotional distress prior to the initiation of radiotherapy, during the course of treatment, or after the completion of treatment. This paper describes treatment experiences from the patients' perspective, reviews the empirical data concerning patients' emotional responses to these treatments, and overviews strategies for reducing patient distress.

Introduction

Of the approximately 78,000 women diagnosed with gynecologic malignancies each year, roughly 60% will receive external and/or internal radiation therapy either as their primary treatment or in combination with surgery or chemotherapy [1]. Despite their effectiveness and widespread usage, these treatments remain mysterious and forboding to many patients. With the attention of the staff directed to treatment planning and execution, the psychological status of patients may be overlooked. When noted, mood disturbances are often viewed as normal and, therefore, not requiring intervention. As treatment progresses, distress often fails to resolve and may actually increase. Even under these circumstances, psychotropic drugs are rarely used [2], and psychological intervention may not be available.

The numerous psychological difficulties to which gynecologic oncology patients may be vulnerable — anticipatory fear, distress during treatment, and continued difficulties posttreatment — not only burden patients but can complicate the efforts of medical personnel. This paper is designed to facilitate more comprehensive care of external and internal radiation therapy patients by providing the following: (1) a description of each treatment from the patient's perspective; (2) a summary of the empirical data concerning psychological responses to each treatment; and (3) suggestions for reducing patient distress.

External radiation therapy (ERT)

Confusion and negative affect are often provoked when the need for ERT is disclosed. Even for the well-educated patient there is misinformation and fears that permanent contamination results from treatment are not uncommon. Other patients optimistically presume radiation attacks only the 'bad' cells, leaving surrounding tissues unaffected. If a patient's only prior knowledge is based on a friend or relative's unpleasant or unsuccessful experiences with ERT, she may begin treatment believing it will be extremely difficult and/or unsuccessful for her,

too [3]. While ERT is the only treatment recommended for some, women with early stage cervical cancer may be offered a choice between ERT and radical hysterectomy. If surgical resection is attempted then aborted, ERT becomes the only mode of treatment. For women recovering from recent surgery and a more negative prognosis, the prospect of ERT may be even more distressing.

During the diagnostic and treatment planning some women may experience communication difficulties with friends and relatives. When a patient does not fully understand the treatment herself, she can misinform her friends and relatives, with further confusion and anxiety as the net result. Relatives and friends may attempt to dissuade the patient from undergoing treatment, particularly if they hold negative beliefs concerning ERT. Occasionally these exchanges escalate, leaving patients alienated from previous sources of support. Wortman and Dunkle-Schetter [4] theorized that cancer patients may experience communication difficulties due to the conflicted feelings of friends and relatives toward cancer. While trying to be sympathetic and supportive, they are frightened by the cancer and wish to avoid its victim. These feelings may be expressed in vague, contradictory communications, such as promising to assist the patient but failing to visit her for long periods of time. Patients may respond by resigning themselves to the isolation, or by increasing their efforts to secure contact via exaggerated complaints of physical or emotional distress.

Once ERT treatments commence, the preceding problems often continue and additional ones may develop. If ERT is not available locally, patients may need to commute each day — an alternative which may heighten patient fatigue and significantly disrupt work and/or family schedules. For those women staying in or near the hospital for ERT, the isolation from family and friends can be lonely. The hours before and after daily treatments are described as boring and frustrating. Dealing with the financial impact of ERT is also a major concern for many patients.

Besides such practical problems, many women find the procedures of receiving ERT and the daily confrontation with one's disease distressing. Fears of human error or machine malfunction are not uncommon. By virtue of its invisible, mysterious nature, ERT may also undermine a patient's already tenuous sense of control and mastery [5]. Exposing the pelvic area to RT technologists can be a daily embarrassment [3]. And, although their field marking tattoos are not readily visible to others, some patients are bothered by them, with reactions ranging from mild irritation with hygiene modifications to more severe distress when the marks are interpreted as visible reminders of their illness. Seeing other patients in the radiation facility, especially those obviously in ill health and with whom the patient identifies, can be particularly disturbing.

Despite such concerns that develop early in treatment, many patients are reluctant to ask questions of the medical team. In Mitchell and Glicksman's [6] research, 82% of ERT patients expressed an unwillingness to approach their physician with concerns. In some instances, patients perceive the staff as too busy with 'more important' aspects of care; others report difficulty in formulating 'intelligent' questions. As Mitchell and Glicksman found, most patients do not have other individuals with whom they can discuss their concerns. These patients often remain confused, fearful, and isolated for the duration of their treatment.

After the first week of ERT, however, a number of patients report less distress. The mechanics of treatment — waiting, exposing the treatment site, rotation of the machine — become routine and the practical problems entailed in receiving ERT may have resolved. While occasionally disturbing, daily contact with other patients may eventually result in new and more accurate knowledge of ERT.

Unfortunately, this ‘honeymoon’ period is often quite brief. Side-effects, such as fatigue, diarrhea, and food intolerance, appear by the second and third weeks of treatment. King and her colleagues [7] found that by the third week the majority of gynecologic patients report significant problems with diarrhea (86%), nausea (30%), anorexia (45%), and fatigue (75%). Nausea and vomiting can be particularly problematic [8] for radiotherapy patients. Such problems are very debilitating, can produce nutritional imbalances, and may be linked to a third difficulty, radiation-induced taste aversions. In a preliminary clinical report, indications of learned food aversions were most common among patients treated in the pelvis (e.g., gynecologic patients) and upper abdomen and were frequently accompanied by reports of nausea associated with treatment [9]. Finally, premenopausal women often begin to experience hot flushes — a salient reminder of the effects of ERT on their fertility and estrogen production.

While these side-effects complicate day-to-day living, they also threaten a woman’s belief that her prognosis is positive. At diagnosis many women with gynecologic malignancies are surprised to hear they are ill, for, other than occasional or mild symptoms, they feel healthy; when side-effects develop, they may begin to view themselves as ill, a deterioration in self-image that damages the sense of invulnerability some patients developed during the ‘honeymoon’ phase. In fact, correlations between the magnitude of disruptive side effects and self-reported negative mood are extremely high ($P = 0.70$) [10]. Women may also begin to question continuing treatment when it ‘makes you feel sicker than the cancer.’

Later in ERT many patients experience further increases in side-effects, particularly nausea and anorexia [7]. Major reductions in activity level, a bland diet, and use of anti-diarrhea and emetic medications may be necessary. With diminished vigor, some women ruefully describe ERT as the focal point of their day, with the hours before and after treatment devoted to dealing with ERT side-effects. While many patients appear to recover some of their strength on weekends [11], this is only a temporary respite from the fatigue that resumes with treatment on Monday.

It might be expected that the final day of radiation treatment would be an occasion of low anxiety and positive thought. When relatively healthy individuals experience medical stressors, they report a drop in anxiety and fear at the conclusion of the procedure [12,13]. Instead, the women we studied reported a different pattern of anxiety responses [14,15]. As might be expected, all patients reported significant fatigue, abdominal pain, anorexia, abdominal cramps, diarrhea, and skin irritation on the last day of treatment. Although they remained the most distressed, women with high pretreatment anxiety were less anxious on the last treatment day than on their first day of treatment. Those with moderate levels of pretreatment distress reported a slight but non-significant diminution in distress by the last treatment. Surprisingly, those women with few worries prior to ERT reported significantly *greater* anxiety on the last treatment day.

While presenting symptoms (e.g., post-coital bleeding) and diagnostic procedures (e.g., biopsies, D and C) may have contributed to sexual difficulties prior to ERT [16], by the end of treatment intercourse may be very difficult due to decreased lubrication and vaginal tenderness. A review of sexual outcomes for gynecologic oncology patients indicates that RT, per se, results in sexual disruption [17]. Estimates of sexual dysfunction in gynecologic oncology patients receiving ERT range from 29% [18] to 75% [19], although preliminary data from our prospective study estimate the magnitude of sexual disruption at 30% [20]. Dyspareunia, a common complaint, is most severe at the end of treatment; it remains present, though of decreasing intensity, during the first post-treatment year. Not surprisingly, this pain can be accompanied by decreased desire, diminished lubrication, lowered arousal, and orgasm disruption. Besides disrupting sexual relationships, vaginal changes may also serve as continued reminders of a cancer diagnosis and treatment.

Although the completion of radiotherapy is met with mixed emotions, many patients do anticipate a fairly rapid return to physical normalcy. However, the patients studied reported their distress actually endured for 1 month or more after treatment [21]. The 'old' side-effects, such as fatigue and hot flushes, linger. King et al. [17] have documented an incidence of nausea in 5%, anorexia in 15%, diarrhea in 15%, and fatigue in 32% of gynecologic patients treated with external beam as long as 3 months previously. The correlation between the severity of lingering side-effects and negative mood range from 0.63 to 0.82 during follow-up [10]. In addition, new long-term complications may begin to emerge. Some, such as radiation proctitis or cystitis and fistulas, may necessitate additional medical interventions.

Finally, many patients perceive themselves as truly ill at the end of ERT and may wonder if it was effective in treating their disease. While follow-up evaluations provide the opportunity for obtaining positive feedback regarding tumor response, patients realize such evaluations also detect treatment failures. Consequently, follow-up evaluations are often approached with great apprehension.

Internal radiation therapy

Intracavitary radiation (ICR)

While ERT involves brief (10–15 min) treatments of the pelvis that extend over a 4–5 week period, ICR involves prolonged (48–96 h) radiation to the tumor mass and/or the surrounding tissues (e.g., the vagina) at risk for recurrence. A metal device designed to hold radioactive pellets is surgically implanted into the vagina and uterus and packed into place with specially treated gauze. During this treatment patients must remain relatively immobile and have limited access to both visitors and medical staff. Few patients have heard of ICR prior to learning they are to receive it; such novelty often contributes to the belief that experimental treatments are being used for a hopeless cancer. Details of the treatment frighten many patients, with fears of isolation or permanent contamination from lengthy radiation exposure common. Hearing other patients' treatment descriptions often has equivocal benefits. Descriptions that do not conform with the patient's negative preconceptions are often rejected, with ease of treatment attributed to the other woman's stoicism. More commonly, however, patients' descriptions are more negative than those of the staff, resulting in confusion and anxiety. Thus, many women temporarily cope with an impending ICR by diverting their thoughts to less distressing topics.

In our research [22] 19 women with early stage cervical or endometrial cancer were studied. Two days prior to ICR, patients' self-reported anxiety (State-Trait Anxiety Inventory [23]) was measured; on the basis of these scores, the sample was divided into high and low pretreatment anxiety groups. Self-reported anxiety was reassessed 12 h before application and 24 h following ICR removal. As Fig. 1 indicates, distinctive patterns of self-reported anxiety were generated by the 2 groups of women. Those women reporting high pretreatment anxiety readily acknowledged distress due to the impending ICR, with a few women attempting to postpone or cancel treatment. While no patients left treatment against medical advice, the staff's persuasive powers were tested and staff-patient relationships strained by such confrontations. The second group, reporting low pretreatment anxiety, was comprised of women who denied distress or concerns and appeared to cope in an exemplary manner. By the night before the ICR, however, their anxiety increased significantly, making them nearly indistinguishable from the first group of patients.

During ICR, both groups reported similar levels of physical discomfort. On a visual analog rating scale of pain the mean rating was 4.4 (range 0–10), indicating significant discomfort despite the liberal use of analgesics. The gauze packing caused burning and bloating sensations, while protruding instruments and drainage irritated the perineum. Gas pains were common,

and many women found catheterization uncomfortable. Virtually every woman complained of aching in the lower back.

Emotional distress was also common. The isolation imposed by radiation protection was lonely and depressing; if perceived as isolation from prompt medical care, it was frightening. Immediate (e.g., When will this end? Where is my pain medication?) as well as distant (e.g., Will this treatment fail? Will it leave me with permanent complications?) concerns were common. With the numerous annoyances (e.g., minimal personal hygiene, extreme dependence upon others, problems eating and occupying one's time, etc.), it is not surprising that many women felt irritable and frustrated during much of their ICR. Approximate removal times were often interpreted literally, with patients extremely disappointed if treatment extended beyond the anticipated removal time. While keenly awaited, many described ICR removal as excruciatingly painful.

The period after ICR is not without difficulties. Our research indicates that fatigue and inactivity remained high at least 24–36 h afterwards. Women with lower levels of self-reported anxiety prior to treatment experienced the greatest physical debilitation and remained quite anxious post-ICR (see Fig. 1). The sudden change in these women — from calm and cooperative behavior pretreatment to resentful, suspicious, and upset behavior post treatment — was disturbing for both the staff and patients. While the mechanisms behind this change in demeanor are unknown, it may be that women who deny concerns prior to a difficult treatment are failing to mentally prepare themselves for its negative, albeit natural, aspects [24]. When preconceived notions and experience fail to coincide, feelings that they were deceived or ill prepared for treatment may surface. Reluctance or refusal to undergo a second ICR can be the net result.

Fifty to 75% of ICR patients receive a second application. Our research has documented that physicians tend to see patients as better adjusted following the second treatment (ICR 2) [25]. However, the belief that patients 'get used to' this noxious medical treatment was not supported by patient reports. Instead, women were *more* anxious and debilitated following ICR 2 than after the first ICR (ICR 1).

As Table I indicates, anxiety patterns differed slightly over time when women reporting either low or high pretreatment anxiety were contrasted. Women low in anxiety prior to ICR 1 were as anxious prior to ICR 2 as they were after ICR 1. While their anxiety decreased slightly the evening prior to ICR 2, by 1 day post treatment it equaled the high level reached when anticipating their first ICR. These women also reported greater discomfort during their treatments. In contrast, women higher in anxiety prior to ICR 1 had anxiety levels prior to ICR 2 similar to those seen after ICR 1. The night before ICR 2 their anxiety increased, only to *decrease* post treatment (see Table I).

Vault radiation (VR)

The form of internal radiation provided after hysterectomy, vault radiation, involves the insertion into the vagina of a barrel-shaped container holding radioactive pellets. Unlike ICR, the insertion is accomplished with local rather than general anesthesia, and treatment lasts 36–48 h. While our data come from ERT and ICR patients, we have clinical impressions of the treatment experiences of VR patients. A number believed they were scheduled for ICR, a confusion often attributable to use of the generic term 'internal radiation' when treatments are discussed with patients. As was true with both ERT and ICR patients, few questions were directed to the staff; consequently, several reported moderate anxiety and feelings of confusion prior to VR.

During VR most women experienced less physical and emotional distress than did ICR patients. Local anesthesia, fewer instruments, and shorter treatment length may account for these relatively positive treatment experiences. However, cognitive factors may be partly responsible, as patients reported perceiving VR distress and discomfort as minor *in comparison* to their negative preconceptions.

After VR women continued to evaluate their treatment more positively than ICR patients. Many were surprised by the relative brevity of treatment, as well as the minimal discomfort associated with removal. And while they reported an increase in fatigue post treatment, VR patients did not report the debilitation common in ICR patients.

Summary and efforts to improve patient adjustment

Our observations of gynecologic oncology patients receiving RT are based on both empirical investigations and clinical experience. We have emphasized the distinctions between the experiences of ERT, ICR and VR patients. For ERT patients, physical side-effects and anxiety predominate during treatment and persist for months post treatment. Women appear to be physically and emotionally overwhelmed by the briefer but more intense ICR treatments. Surprisingly, those who seemed least distressed prior to the ICR responded most negatively post treatment and, contrary to clinical anecdotes, the second ICR was more difficult than the first. In contrast, VR patients experienced fewer difficulties during and after treatment, and their pretreatment distress appeared partly attributable to confusion over treatment type. There are also experiences common to all the patients studied. Certain times are particularly distressing for patients, such as the diagnostic period, initiation of treatment, and appearance of side-effects. Our data also indicate the period of recovery continues to be stressful, with many patients failing to perceive treatment as over for a considerable period of time.

Although the type of treatment received is influential, individual differences in anxiety may also help to explain fluctuations in patients' emotional status. In the descriptive investigations [15,25] those who appear least distressed before treatment often show the worst adaptation after treatment. Patients who approach treatment overtly anxious remain distressed, albeit slightly less so, over the source of treatment. These phenomena have confirmed the adaptive function anticipatory, realistic concerns may play in coping with stresses of medical treatment [24].

When individual differences (typically coping style) have been examined as mediators of intervention effectiveness, they have not added predictive value. For example, Rainey [26] examined both avoidant-vigilant and repression-sensitization coping styles and found neither to moderate the effectiveness of a patient education program. One other variable, knowledge of cancer diagnosis, has been somewhat predictive of outcome [27]. However, since this variable is highly correlated with emotional distress (i.e., those who 'do not know the diagnosis' report lower overall emotional distress than those classified as 'knowing the diagnosis'), it may be analogous to classifying patients at pretreatment, for example, into low, moderate, and high anxiety groups, when examining post-treatment outcome.

While this paper focuses upon specific radiotherapy experiences gynecologic cancer patients may face, intervention to alleviate distress may take many forms. As it has been used effectively with many types of cancer patients at various points in their illness [e.g., 28,30], general counseling or psychotherapy may be offered. Forrester et al. [27] provided weekly individual psychotherapy to patients undergoing 6 weeks of ERT. Patients were free to discuss whatever they chose, although for the majority, the sessions consisted of 'supportive therapy with educational, interpretive, and cathartic components' [27, p. 23]. Improved functioning was found between patients receiving psychotherapy and no treatment control subjects. Emotional

symptom scores were significantly lower for the treated patients at the termination of radiotherapy and these gains were maintained at 2 months post treatment. In addition, fewer side-effects were reported at the 1 month follow-up, including a lower severity of anorexia, nausea and vomiting, and fatigue.

Other intervention models have information provision as a major component. Patients' descriptions of themselves as ill informed and confused [31] suggest that more effective methods of providing treatment information need to be implemented. Assessment of the patient's knowledge of RT during initial consultation and treatment planning provides an opportunity to distinguish treatment types (e.g., ICR vs. VR) and intents (definitive vs. palliative), as well as the differing prognoses for various sites (e.g., ovary vs. cervix). Research on patient preparation suggests that such information needs to be simplified. While one risks insulting knowledgeable patients, understanding should not be assumed and more knowledgeable patients' questions can provide a guide for further, more complex explanations.

Patients should be provided with information about routine procedures and normal bodily sensations entailed in treatment, as well as specific suggestions for coping (e.g., dietary changes, relaxation exercises, etc.) with radiotherapy stressors. Such a strategy was implemented by Rainey [26]. Thirty patients were individually shown a 12 min high-information slide-tape program at the beginning of ERT. Interestingly, the control condition consisted of 30 patients provided with the booklet, 'Radiation therapy and you' written by the National Cancer Institute in the United States. Testing of patient knowledge of radiation therapy immediately after the intervention revealed significant differences in favor of the slide-tape group. Not unexpectedly, by the end of treatment there were no knowledge differences between the groups. The levels of anxiety and overall mood disturbance were comparable between groups at the beginning of treatment, but during the last week of treatment both were significantly reduced for the slide-tape group.

Instead of providing all information to patients on one occasion at the start of treatment, another alternative is to provide it as it becomes most relevant. For example, Israel and Mood [32] provided sensory and procedural information early in the course of ERT, information regarding treatment side-effects and management at the treatment midpoint, and emotional issues were addressed toward the end of ERT.

A special category of information that gynecologic oncology patients may need is that regarding sexual functioning and the strategies for preventing sexual difficulties. As indicated previously, radiation therapy appears to result in sexual disruption [17]. Dyspareunia, the most frequent complaint, appears to be more common and severe among women receiving both external beam and intracavitary treatments, although patients receiving only external therapy report this symptom too. The magnitude of dyspareunia and associated desire, lubrication, arousal, and orgasm dysfunction may be reduced by appropriate intervention. Women should be supplied with vaginal dilators; those women not sexually active should be instructed to use their dilators regularly (e.g., 2–3 times/week). If the frequency of intercourse is low (i.e., less than once/week), women should use a dilator intermittently. Since some women have difficulties with the dilator regimen, instruction in usage should be given during a pelvic examination conducted while the woman is receiving radiotherapy, with continued dilator usage monitored and encouraged during follow-up visits. Use of a sterile lubricant, both with dilator usage and intercourse, can reduce friction and alleviate dryness. If not contraindicated, topical estrogen cream may promote healing and improve the vaginal epithelium [33].

Once information has been delivered, understanding should be assessed. Some researchers have utilized multiple-choice tests to assess patients' understanding [26,32]. An alternative we have used involves asking patients to explain their treatment to us as if they were describing

it to a friend or a prospective patient. This strategy appears to put patients at ease, and provides an opportunity for reinforcing understanding as well as correcting misconceptions. Encouraging patients to ask questions at any point during treatment is also important. Patients need acknowledgement of how difficult it is to ask questions when bewildered, as well as reassurances that no question will be considered unimportant.

Finally, the frequent contact of the treatment team with patients places them in a favorable position to detect emotional distress in RT patients [34]. As discussed earlier, data suggest that those patients most vulnerable to distress are often the ones making good medical progress and denying the existence of emotional distress or those unaware of their diagnosis early in treatment. For many, the assurance that distress is normal may provide the impetus for the disclosure of emotional problems. While it is difficult to know when psychological treatment is warranted, Mages and Mendelson [35] have targeted patients with a prior history of emotional problems, those whose diagnosis and treatment interferes with their normal life or causes chronic discomfort, and socially isolated patients as those most likely to need psychological assistance during cancer treatments. Our experience suggests that over-referral of 'minor' difficulties may be more advantageous than delaying treatment. Brief therapy or crisis intervention may be beneficial, and psychotropic medication also may be warranted for the level of depression or anxiety many cancer patients experience [2].

Our understanding of gynecologic oncology patients receiving RT has advanced, but research needs to continue to further understand which patients need help, what kinds of interventions are most effective, and when assistance should be provided. We hope these efforts will continue to improve the course of radiation therapy for gynecologic oncology patients.

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Fig. 1.

Changes in patients' self-reported anxiety as assessed by an anxiety questionnaire (State-Trait Anxiety Inventory [23]) administered 48 h and 12 h before ICR application, and 24 h following removal. Patients were assigned to the low or the high pretreatment anxiety groups based on their score on the anxiety questionnaire administered 48 h before application.

TABLE I

MEAN STATE ANXIETY SCORES FOR PATIENTS RECEIVING TWO INTRACAVITARY RADIATION TREATMENTS

This table depicts changes in patients' self-reported anxiety as measured by a questionnaire (State-Trait Anxiety Inventory [23]) for women receiving 2 ICR treatments. Patients differing in the magnitude of self-reported pretreatment state anxiety (i.e., high vs. low) 48 h before the ICR were reassessed 12 h before the ICR and 24 h following its removal for both the first and second ICR. The higher the number, the greater the magnitude of self-reported anxiety. Multiple comparison analyses were conducted separately with the data from the first and second ICR treatments. Within each ICR, common superscripts across levels indicate no significant differences, while different superscripts indicate significant differences ($P < 0.05$).

Level of pretreatment anxiety	First ICR treatment time			Second ICR treatment time		
	48 h before	12 h before	24 h after	48 h before	12 h before	24 h after
High						
M	53.0 ^a	52.3 ^a	46.3 ^a	46.4 ^a	54.2 ^b	49.6 ^{a,b}
S.D.	4.7	5.9	6.7	10.5	10.4	10.3
Low						
M	40.8 ^b	51.2 ^{a,c}	47.8 ^{a,c}	44.5 ^a	43.0 ^a	49.8 ^{a,b}
S.D.	2.4	10.1	4.0	0.6	4.4	12.8